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Statewide Parent Advocacy Network, Inc.

Empowered Families: Educated, Engaged, Effective!

Family Voices-NJ Comments on the Patient Protection and Affordable Care Act: Requirements for Group Health Plans and Health Insurance Issuers Under the Patient Protection and Affordable Care Act Relating to Preexisting Condition **Exclusions, Lifetime and Annual Limits, Rescissions, and Patient Protections: Final Rule and Proposed Rule** Submitted August 9, 2010

Thank you for the opportunity to comment on the preexisting condition exclusions. lifetime and annual limits, rescissions, and patients protections under the Patient Protection and Affordable Care Act. Family Voices is a national network that advocates on behalf of children with special healthcare needs and works to "keep families at the center of children's healthcare;" our NJ Chapter is housed at the Statewide Parent Advocacy Network (SPAN), NJ's federally designated Parent Training and Information Center, Family-to-Family Health Information Center, and chapter of the Federation of Families for Children's Mental Health. The NJ Coordinator also serves in a voluntary capacity as the NJ Caregiver Community Action Network representative for the National Family Caregivers Association for caregivers across the lifespan, as well as volunteering for the local and state chapter of the National Alliance on Mental Illness.

Supplementary Information I. Background

We strongly support the definition of "group health plan" inclusive of both insured and self-insured plans under ERISA. We also agree that the Affordable Care Act requirements can not be "construed to supersede any provision of State law which establishes, implements, or continues in effect any standard or requirement solely relating to health insurance issuers in connection with group or individual health insurance coverage except to the extent that such standard or requirement prevents the application of a requirement" of the Affordable Care Act. In NJ for example, we already have dependent coverage up to age 31, mental health parity, and guaranteed issue for preexisting conditions.

II. Overview of the Regulations:

A. Prohibition of Preexisting Condition Exclusions

We strongly support that Affordable Care Act will include both group and individual plans effective January 1, 2014. We also strongly support that for enrollees who are under 19 years of age, this is effective September 23, 2010. Until then the HIPAA provisions (applying to group plans only and allowing "limited" exclusions) are in effect. We are extremely concerned that "these interim final regulations do not change the HIPAA rule that an exclusion of benefits for a condition under a plan or policy is not a preexisting condition exclusion if the exclusion applies regardless of when the condition arose relative to the effective date of coverage." We are concerned that this language will be misused to deny coverage. We have heard cases in which infants with birth defects were denied coverage due to "preexisting condition" exclusions. Although we appreciate the interim high risk pools until 2014, we are also concerned because the individual had to be uninsured for 6 months, as 60% of bankruptcies are due to medical debt (source: Families USA). We are also concerned that for "grandfathered" plans, the preexisting condition exclusion will continue to apply to group but not individual plans.

B. Lifetime and Annual Limits

We strongly support that the prohibition on lifetime and annual benefits applies to both group and individual plans, including self-insured plans. We understand that flexible spending accounts (FSAs) are limited to "\$2500 (indexed for inflation) per year, beginning with taxable years in 2013". We also understand that the "annual limit rules do not apply to health FSAs" and that the rules also do not apply to Medical Savings Accounts (MSAs), Health Savings Accounts (HSAs), and Health Reimbursement Agreements (HRAs).

The statute does allow "restricted annual limits" on "essential health benefits", and note that regulations on essential health benefits are forthcoming. We understand that plans may have lifetime or annual benefits on non-essential health benefits and look forward to the definition of such. We are also concerned that for "grandfathered" health plans, this applies only to group, not individual plans.

We strongly disagree with the proposed amounts for annual limits of \$750,000 [plan or policy years] until September 23, 2011; \$1.25 million until September 23, 2012; and \$2 million until January 1, 2014. Only 8.2% of large plans have annual limits. However most plans currently have lifetime limits (which could be reached in a year with a catastrophic illness) ranging from \$1-5 million; less than 25% of plans are currently under \$2 million. We have heard cases where a mother had a \$5 million bill by the time her newborn left the hospital; another mother had a \$77,000 bill for her newborn who died never having left the hospital. There have been cases where individuals with cancer had to stop or delay chemotherapy because they reached the insurance cap. Personally, just for one of three specialist visits that day, we are receiving bills for \$12,000 and going to Children's Hospital every two weeks pre-transplant for our daughter with a range of special health care needs. We understand that these proposed annual limits are "minimums. . . [and] plans may use higher annual limits or impose no limits". However, we have found that once a minimum is established, it

typically becomes the standard. For example, when a 2 hour minimum was proposed for early intervention services, most children in our state received 2 hours of services per week, regardless of the severity of the disability. Clarification is needed on the statement that the "minimum annual limits for plan or policy years beginning before 2014 apply on an individual-by-individual basis." We are also deeply concerned that the regulations allow for the Secretary to "establish a program under which the requirements relating to restricted annual limits may be waived if compliance with these interim final regulations would result in a significant decrease in access to benefits or a significant increase in premiums". We look forward to the forthcoming guidelines on the waiver process.

We agree that if an individual reached their limit prior to these regulations but is otherwise still eligible, that they must be provided with a notice. We further agree that if said individual is no longer enrolled, that an opportunity for reenrollment must be given. We understand that in the individual market, this does not apply if the contract was not renewed or otherwise is no longer in effect. We agree that if an individual reached the limit and other family members are still covered that it would still apply. We support that they would be considered a "special enrollee" and afforded the opportunity to enroll in benefit packages available to similarly situated individuals.

Regarding retention of grandfathered status, we agree that if a plan did not have an annual or lifetime limit on March 23, 2010, it will lose its status if it imposes an annual limit. If a plan previously had a lifetime but no annual limit, it will lose status if it adopts an annual limit that is lower than the lifetime limit on March 23, 2010. If a plan previously had an annual limit but decreases it, it will lose its status.

C. Rescissions

We understand that a plan may not rescind coverage except in cases of fraud or intentional misrepresentation. We strongly support that this applies to both group and individual plans. The statue clearly states that plans "cannot cancel, or fail to renew". We strongly agree that a cancellation that "voids benefits paid up to a year before the cancellation is also a rescission". We support 30 days advance notice when rescission is permissible. We understand that besides fraud, nonpayment of premiums, withdrawal of the product from the market, movement outside the service area, or for cessation of association membership for bona fide association coverage, would result in cancellation. However, we would caution that there must be protections in place, for example, against allowing an employer to transfer an individual "outside the service area", particularly if they or a family member develops a serious condition. We strongly support the HIPAA nondiscrimination provision still in effect that plans may not set eligibility rules based on health status and evidence of insurability, for example regarding domestic violence or disability. Although we strongly support "limits on the ability of plans...to vary premiums and contributions based on health status" and that additional protections will be in effect January 1, 2014 (including guaranteed issue), we feel that more is needed in this area. For example, changes to premiums will not cause a plan to lose grandfathered status. We strongly disagree with this as plans will merely

transfer cost sharing prohibition requirements by increasing premiums. Indeed, we have seen double digit increases in premiums prior to enactment from corporations because "healthcare reform *might* happen" in backlash. We've also witnessed increased premiums, lower wages, no raises or bonuses, etc. in anticipation. We are hoping for monitoring and enforcement, including sanctions, for unreasonable premium increases as stated in the Act. We believe that unreasonable premium increases should cause a plan to lose its grandfathered status and urge tracking this for all plans prior to the changes in 2014.

D. Patient Protections

1. Choice of Health Care Professional

We agree that if enrollees are required to pick a primary care provider, then the choice of designee is allowed as long as it is a participating provider. This includes pediatricians in the case of children. We also strongly support access to obstetrical/gynecological care without prior authorization as long as it is in-network.

2. Emergency Services

We strongly agree that emergency services can be provided without prior authorization of the primary care provider, even if it is out-of-network. We also agree that cost-sharing for emergency services that are out-of-network "cannot exceed the cost-sharing requirements that would be imposed if the services were provided in-network". However, out-of-network providers may bill enrollees for the difference with which we disagree. While we understand the formula using in-network, out-or-network, and Medicare rates, in an emergency families will be going to the medical facility closest to their location and shouldn't be penalized financially in true emergency situations. We agree with the definition of emergency utilizing the "prudent layperson" definition. We strongly disagree that this statute will not apply to grandfathered plans.

III. Interim Final Regulations and Request for Comments

We strongly agree that the "six-month period between the enactment of the...Act and the applicability of many of the provisions would not allow sufficient time for the Departments to draft and publish proposed regulations, receive and consider comments, and draft and publish final regulations". We also agree that the "Secretaries further find that issuance of proposed regulations would not be sufficient because the provisions of the...Act protect significant rights" and that "Proposed regulations are not binding..." In summary, we fully support the Department's determination that "it is impracticable and contrary to the public interest to engage in full notice and comment rulemaking before putting these regulations into effect, and that it is in the public interest to promulgate interim final regulations." However, we encourage widespread notice of the interim final regulations as soon as practicable and development of a process that allows for robust public input, including regional opportunities to hear concerns and recommendations from families and individuals.

IV. Economic Impact and Paperwork Burden

A. Summary-Department of Labor and Department of Health and Human Services

We strongly support the patient protections under preexisting conditions, lifetime and annual limits, and rescissions.

B. Executive Order-Department of Labor and Department of Health and Human Services

We agree that this regulation is "economically significant" (...annual effect on the economy of \$100 million in any one year)".

1. Need for Regulatory Action

a. Preexisting Condition Exclusions

We strongly agree that action was needed as prior to the Affordable Care Act, plans in 45 states could deny coverage, benefits, or charge higher premiums. We appreciate that while this takes effect January 1, 2014 that for enrollees under age 19 it will begin September 23, 2010.

b. Lifetime and Annual Limits

As stated previously, we strongly agree that there should be parameters around lifetime and annual limits. However, we feel the annual limits in the statute are much too low.

c. Rescission

We strongly support prohibition on rescission or cancellation of policies except in cases of fraud, or non-payment of premiums. We would caution however that non-payment must be monitored so it's not used as an excuse for cancellation so plans can't say they didn't get "the check in the mail". This new statute will help over 10,000 individuals who lost coverage per year due to rescissions.

d. Patient Protections

As stated earlier, we strongly support enrollee choice of primary care providers, including pediatricians. We also support no need for prior authorization of Ob-Gyn or emergency care.

2. Prohibition of Preexisting Condition Exclusions

a. Summary

As stated above, we support that grandfathered group plans must comply but we disagree that this does not affect individual grandfathered plans.

b. Estimated Number of Affected Individuals

We agree that for children this will affect the uninsured as well as children who have individual insurance with a rider on preexisting conditions. We agree with the estimate of 540,000 uninsured children with preexisting conditions. About half of these children have parents who are also uninsured and about 60,000 have parents who turned down ESI. We agree the group most affected will be the 10,000 children whose parents have non-group coverage, and it is uncertain if the plan refused a preexisting condition, the new plan will be required to cover the child. We agree with the mid-range estimate that 50% of uninsured children whose parents have individual coverage will be covered, and 15% of uninsured whose parents were also uninsured will get coverage. In addition there are 90,000 children with individual coverage with a waiver whose parents may remain in grandfathered plans or will switch to new plans but at higher premiums so estimates are difficult. In total, considering all these factors we agree with the midrange estimate that 51,000 children with preexisting conditions will obtain coverage.

c. Benefits

We strongly agree that children who have health insurance have better outcomes. Children and adults who are uninsured are diagnosed on average 2 years after their covered counterparts. Early diagnosis and intervention are is not only cost effective when disease is easier to treat, but more importantly results in decreasing morbidity and mortality due to better health outcomes. We also agree that expanded coverage will reduce medical bankruptcies. Families will also be able to switch jobs more easily, particularly those who have children with preexisting conditions.

D. Costs and Transfers

It is estimated that the additional costs of newly covered children will be spread across policies in the individual market that are not grandfathered health plans. We agree that unfortunately that "much of the cost of care for newly-covered children with preexisting conditions is likely to be borne by the parents who purchase coverage..." The estimated increase in premium is 1%, and one half of 1% in States without community rating. Similarly, "in States that require rating...much of the additional cost for eliminating condition waivers will be spread across the insured population, while in States without rating...much of the additional costs will be borne by the parents..." However, even in states with community ratings, "the cost and transfer effects will be relatively small, at most a few tenths of a percent over the next few years".

3. No Lifetime or Annual Limits

a. Summary

As stated earlier, we are concerned with "restricted" annual limits regarding essential health benefits and look forward to the forthcoming definitions. Also, as shown in Table 3.1 only 19% of plans have lifetime limits under \$2 million, while approximately 82% had lifetime limits over \$2 million or no limits (37%).

b. Estimated of Affected Individuals

In the first year, it is estimated that less than .08% of large employer, 2.6% of small, and 2.3% of individual market plans would have to raise their annual limit to \$750,000 affecting an estimated 1, 670,000 people. In the second year, it would affect 3,278,250 individuals and in the third year 8,104,500 across all markets. It is further estimated that this would extend coverage to 2,700-3,500 people per year for annual limits and 18,650-20,400 people for year for lifetime limits.

c. Benefits

As stated above, we agree that this will help those with catastrophic illnesses like cancer but also improve healthcare access for all and continuity of care. In addition to decreased morbidity and mortality, there would also be improved workplace productivity due to better health outcomes.

d. Costs and Transfers

We agree that "given the relatively small proportion of people who exceed the benefit limits...the Departments anticipate such transfers to be minimal when spread across the insured population (at a premium increase of one-half of a percent or less for lifetime limits and one-tenth of a percent or less for annual limits)". Again, in the individual market, these costs will be borne by policyholders. As stated earlier, we are concerned that this statute does not affect the individual plans that are grandfathered. Overall, we agree that individuals will not have to spend down and enroll in Medicaid, which will result in reductions in both Medicaid and uncompensated care.

e. Enrollment Opportunity

As stated before, we agree with the opportunity for reenrollment for those who have reached their limit in group plans, or in individual plans unless the contract isn't renewed (except if other family members are still covered).

f. Alternatives

We thank the Departments for ensuring "access to needed services with a minimal impact on premiums". We appreciate that the Departments examined current annual limits, impact on premiums, individuals exceeding annual limits, and plans switching to annual limits if lifetime limits were prohibited. We are deeply concerned that plans will offset premium increases by increasing cost sharing to families. As stated earlier, we

are also concerned with the Secretary establishing a waiver if there would be a significant decrease in access to benefits or a significant premium increase.

4. Rescissions

a. Summary

As mentioned earlier we strongly support prohibiting rescissions except for fraud/nonpayment and 30 days notice when permissible. We are pleased that this applies to insured and self-insured plans.

b. Estimated Number of Affected Entities

We agree this will have the largest impact on the individual market. The final estimate is that this will affect 17 million non-elderly policyholders and prevent 10,700 rescissions per year.

c. Benefits

Again, we agree that this will avoid breaks in continuity of care which leads to increased morbidity/mortality and even negatively impacts work productivity.

d. Costs and Transfers

Although insurers may use more resources prior to issuing policies, we agree that this would be off-set by "decreased costs associated with reduced post-claims underwriting". Post-claims underwriting occurs when insurance companies retroactively examine expensive claims and applications. We agree that there were "questionable practices...including...rescinding coverage even when discrepancies are unintentional or caused by others, for conditions that are unknown to policyholders, and for discrepancies unrelated to the medical conditions for which patients sought medical care" and that the statute will prohibit this. Rescissions are rare in the group market and even in the individual market only affect .15% of policies so we agree with the Departments impact estimate "to be small".

5. Patient Protections

We agree with the previously mentioned protections regarding choice of primary care provider and emergency services. It is only if the plan "has not negotiated with any provider for the delivery of health care but merely reimburses…" that it is not subject to this statute (except for emergency services).

a. Choice of Health Care Professional

i. Designation of Primary Care Provider

Summary

We agree that if the provider is in network, the enrollee should designate their choice.

Benefits

We agree that this will improve medication compliance, wellness, and decrease malpractice claims. Research shows that individuals who have a PCP also have reduced costs and lower mortality rates. We agree this will also decrease emergency care and hospitalizations. For adults, prevention could include cancer screenings rather than waiting until the condition is more serious, costly, and results in higher morbidity and mortality.

Costs and Transfers

We agree that with no changes in coverage or cost-sharing that "the number of affected entities is very small, leading to small additional costs...there will be negligible transfers due to this provision".

ii. Designation of Pediatrician as Primary Care Provider

Summary

We agree that for children the PCP should be a pediatrician as illnesses may manifest differently in children.

Estimated Number of Affected Entities

We agree "due to lack of data on enrollment in managed care...by age...the Departments are unable to predict the number of enrollees and plans that would be affected by these provisions".

Benefits

In addition to the benefits described above for adults regarding medication compliance, wellness, decreased E.R./hospitalizations, etc. we also agree that health promotion for children would affect the epidemic of obesity and resulting secondary conditions like diabetes. It is estimated that even a 1% reduction would save over \$260 million. It is for this reason that we strongly believe that prevention initiatives must be applicable for all plans. We disagree that the grandfathered plans are not required to cover preventive health without cost sharing. Preventive health is not only cost effective but more importantly results in better health outcomes. Particularly for children, wellness initiatives such as immunizations and lead screening are especially important. We strongly recommend for children that the Bright Futures guidelines, endorsed by the American Academy of Pediatrics, be utilized for children's wellness and prevention. For more information see http://brightfutures.aap.org.

Costs and Transfers

Again, it is difficult to estimate due to the previously mentioned limits on data but we agree that "the costs for this provision are likely to be small".

iii Patient Access to Obstetrical and Gynecological Care

As stated earlier we agree this shouldn't require prior authorization. This is also important in states like ours that have minor consent to treatment.

Estimated Number of Affected Entities

In NJ and 14 other states, direct access was not previously mandated. Further self-insured plans were also previously exempt under ERISA. We disagree however that this should apply only to non-grandfathered plans.

Benefits

It is estimated that 42,000 women die annually from breast cancer and 4,000 lives could be saved if screening rates increased, as well as continuing declining rates of cervical cancer from pap smears.

Costs and Transfers

Although data is limited, we again agree with the Departments regarding additional costs "to be small".

b. Coverage of Emergency Services

i. Summary

As stated previously, we agree that the prudent layperson definition holds but disagree with any extra charges for out-of-network services in an emergency. We also disagree that this should not apply to grandfathered plans.

ii. Estimated Number of Affected Entities

We agree that "there are no available data...for national estimates of the number of plans (or...enrollees)" but we agree that informally if could affect 2.1-4.2 million policyholders regarding differing out of pocket requirements, but since the majority have identical in and out of network requirements the number affected "would be smaller".

iii. Benefits

We agree that "in an emergency...the choice of an in-network provider may not be available" which is why we feel the cost should be the same. We disagree that in a true

emergency individuals would "delay or avoid seeking necessary treatment when they cannot access a network provider, ...this...may result in more timely use of necessary medical care" however agree that insured individuals are less likely to delay care so the effect would be small.

iv. Costs and Transfers

We agree that "it is likely to be less than one-tenth of one percent of premiums..." but we disagree that it should only apply to non-grandfathered plans.

c. Application to Grandfathered Health Plans

We understand that some provisions do not apply.

d. Patient Protection Disclosure

We agree that patients should know their rights, be able to choose PCPs, and access Ob-Gyn and emergency services without prior authorization. We will discuss the model language later in the document.

6. Combined Effects of the Insurance Market Reforms

a. Summary

We understand that patient protections are addressed but that dependent care coverage and grandfathered plan status were addressed in other regulations. We also know that prevention, essential health services, and appeals will be forthcoming.

b. Benefits

We agree that there will be significant economic impacts on consumers. But most importantly there will be decreased morbidity and mortality resulting from better health outcomes. We also agree that there will be reductions in medical risk through pooling. We previously agreed with improved productivity, reduction in disability and preventable illness, job motility, and shifts in uncompensated care and Medicaid (2/3 of previously uncovered costs which if passed on from private sources in the form of lower prices could lead to lower premiums).

c. Costs and Transfers

We agree the burden will be distributed over a wider insured population. We also agree that it is difficult to estimate accurately due to interaction of provisions such as if a policy was rescinded, then restored with no lifetime cap, and it's a child under 26, who has a preexisting condition.

D. Regulatory Flexibility Act-Department of Labor and Department of Health and Human Services (Note it skips from B. to D. there is no C.?)

We agree that because the Department "made a good cause finding that a general notice of proposed rulemaking is not necessary" they are not required to "either certify that the regulations would not have a significant impact on a substantial number of small entities or conduct a regulatory flexibility analysis." Although we do feel that there will be a likely impact on small entities, we do not have any suggestions at this time on minimizing this impact.

E. Special Analysis – Department of the Treasury

We agree that "this Treasury decision is not a significant regulatory action" and that therefore "a regulatory assessment is not required."

F. Paperwork Reduction Act

1. Department of Labor and Department of Treasury

We would support requirements that there must be a statement in any plan materials describing benefits. We also agree with minimizing the burden by allowing plans to use electronic submission of responses to these requirements as long as there is verification of receipt of the same.

a. Notice Relating to Lifetime Limits

Current estimates are that 29,000 qualify for this enrollment right. There are 139.6 million individuals in ERISA plans, 63% of which have lifetime limits. However the estimated costs seem extraordinarily high with clerical rates at \$26 and legal professionals at \$119 hour.

b. Notice Relating to Rescission

We agree that about 100 policies are rescinded annually which would require 1600 notices. However we feel that the rates stated above for clerical and legal staff are too high.

c. Patient Protection Disclosure

We agree that there are 339,000 ERISA plans who would have to notify 8 million enrollees but we disagree with the \$5.8 million (particularly if 38% of notices are electronic and would suggest receipt confirmation) due to the rates above.

2. Department of Health and Human Services

a. Notice Relating to Lifetime Limits

Current estimates are that 13, 182 qualify for this enrollment right in individual plans. It is estimated to cost \$4.7 million across plans but we disagree with the rates above.

b. Notice Relating to Rescission

We agree that about 10,700 policies are rescinded annually in the individual market all of which would require notices. However we feel that the rates stated above for clerical and legal staff are too high.

c. Patient Protection Disclosure

We agree that there are 14, 000 government plans who would have to notify 2.6 million enrollees but we disagree with final amount due to the rates above.

G. Congressional Review Act

We agree that these interim final regulations are "subject to the Congressional Review Act provisions of the Small Business Regulatory Enforcement Fairness Act".

H. Unfunded Mandates Reform Act

We agree that these rules are not subject to the Unfunded Mandates Reform Act because they are being issued as interim final regulations.

I. Federalism Statement

We agree these rules have federalism implications because it directly affects "States, the relationship between the national government and the States, or on the distribution of power and responsibilities among various levels of government". However this is mitigated by the fact that most states "will enact laws or take other appropriate action resulting in their meeting or exceeding the Federal standard."

V. Statutory Authority

Lastly, the Department requested comments on the model language notice on disclosure. We would modify it as follows:

(A) For plans and issuers that require or allow for the designation of primary care providers by participants or beneficiaries, insert:

[Name of group health plan or health insurance issuer] generally [requires/allows] the designation of a primary care provider. You have the right to choose any primary care provider who participates in our network and who is available to accept you or your family members. [If the plan or health insurance coverage designates a primary care provider automatically, insert: Until you make this choice, [name of group health plan or

health insurance issuer] chooses one for you.] For information on how to select a provider, and for a list of the participating providers, contact the [plan administrator or issuer] at [insert contact information].

(B) For plans and issuers that require or allow for the designation of a primary care provider for a child, add:

For children, you may choose a pediatrician as the primary care provider.

(C) For plans and issuers that provide coverage for obstetric or gynecological care and require the designation by a participant or beneficiary of a primary care provider, add:

You do not need a referral from [name of group health plan or issuer] or from any other person (including a primary care provider) in order to obtain access to obstetrical or gynecological care from a health care professional in our network who specializes in this area. The health care professional, however, may be required to comply with certain procedures, including obtaining prior authorization for certain services, following a pre-approved treatment plan, or procedures for making referrals. Note: clarification is needed on how a participant would know these requirements. For a list of participating health care professionals who specialize in obstetrics or gynecology, contact the [plan administrator or issuer] at [insert contact information].

As the Family to Family Health Information Center (F2F HIC) in NJ, we work with families and professionals to help them collaborate to improve health care access and quality for children with special healthcare needs. Thank you again for the opportunity to comment on preexisting condition exclusions, lifetime and annual limits, rescissions, and patients protections under the Patient Protection and Affordable Care Act.

Sincerely,

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Our Mission: To empower families and inform and involve professionals and other individuals interested in the healthy development and educational rights of children, to enable all children to become fully participating and contributing members of our communities and society.